

PILGrimage to New York

For more than a decade, the NIEHS has strived to enhance community participation in the research-setting agenda. Under the leadership of Kenneth Olden, the institute has established a number of mechanisms by which representatives of community organizations with a variety of interests can voice their concerns, ideas, and recommendations for making environmental health research more responsive to community needs. One of these mechanisms is the Public Interest Liaison Group (PILG), which met 4-5 September 2003 with NIEHS leadership and the directors of five institute-funded research centers in and near the New York area to discuss ongoing studies and outreach efforts.

The PILG is composed of leaders representing 29 nongovernmental organizations that advocate for disease-specific interests or at-risk populations. These leaders meet with NIEHS staff and NIEHS-supported researchers to help develop a research agenda that is responsive to public constituents. As Olden said at the meeting, "The public wants to be included at the onset of research, and the researchers are also looking for the community's advice in setting priorities." The PILG provides a mechanism to achieve both.

An example of how public interest organizations have collaborated with the NIEHS on setting research agendas is represented by the work of breast cancer advocacy groups. Karen Joy Miller, founder and president of the Huntington Breast Cancer Action Coalition, and other members of the PILG and the breast cancer advocacy community were instrumental in providing input into planning the new NIEHS Breast Cancer and the Environment Research Centers to be opened around the country, and in requesting that the NIEHS include new Community Outreach and Translation Cores within these centers. "It is a real sign that NIEHS truly listens," said Miller.

The September meeting included the directors and many research staff of five NIEHS-funded environmental health sciences and children's environmental health centers. Represented were the Mount Sinai School of Medicine, New York University, Columbia University, the University of Medicine and Dentistry of New Jersey, and The Johns Hopkins University.

The center directors and staff presented highlights of the research being conducted at their institutions that contributes to the state of the knowledge of how environmental factors may affect a variety of diseases and effects. For example, Regina Santella, director of the Center for Environmental Health in Northern Manhattan at Columbia University, relayed information on a new study using meconium as a biomarker of fetal exposure to pesticides. George Lambert, a researcher at the Environmental and Occupational Health Sciences Institute at the University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School, described a program in its second year of funding to examine new evidence linking an increasing incidence of autism with environmental factors such as exposure to lead, methylmercury, and ethanol. Members of the PILG had the opportunity to discuss these research findings with the center directors and NIEHS staff, and to make recommendations on current and future research directions. "Priority setting is what this event is about," said Olden.

Members of the PILG with expertise in autoimmune and respiratory disease presented the work that their organizations are doing in advancing research and advocacy. Several of the presenters focused on supporting research through new funding mechanisms, including partnering and collaborating with the NIEHS.

Other presenters focused on communication to the public and translation of research results. Patricia Green, director of development for the Allergy & Asthma Network Mothers of Asthmatics, presented her organization's efforts to bring disease management tools to asthmatic children through innovative web-based educational



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programs. One of these is Breatherville, USA, a website located at <http://www.breatherville.com/breatherville.htm> where parents and children can find tips for managing child asthma and allergies, including advice on coexisting with pets, reducing allergens at home, and dealing with classmates and teachers who may not know about asthma. In another outreach initiative, Allen Dearry, director of the NIEHS Division of Research Coordination, Planning, and Translation, announced the development of an interagency meeting that will collect the expertise of the scientific and advocacy communities to devise best practices for asthma interventions, research, and prevention.

Closing the meeting, New York senator Hillary Rodham Clinton spoke of her support of the work that the NIEHS has done in making sure that research outcomes are responsive to public concerns. She remarked that the PILG members are "people who have taken their own personal experience of disease and translated it into action on behalf of a better environment."

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